**Journal of Neonatal Surgery**
***ISSN(Online): 2226-0439***
***Vol. 14, Issue 1s (2025)***
*https://www.jneonatalsurg.com*

OPEN ACCESS

# A Study on Parental Awareness Regarding ROP Eye Screening and Follow-Up Compliance in Infants Diagnosed with Retinopathy of Prematurity at A Tertiary Eye Care Centre in Northern India

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Cite this paper as: Dr. Madhulika Sinha, Dr. Abhishek Anand, Dr. Manish Kumar Karn, (2025) A Study on Parental Awareness Regarding ROP Eye Screening and Follow-Up Compliance in Infants Diagnosed with Retinopathy of Prematurity at A Tertiary Eye Care Centre in Northern India. *Journal of Neonatal Surgery*, 14 (1s), 1384-1391.

## ABSTRACT

**Background:** Retinopathy of Prematurity (ROP) causes preventable childhood blindness in preterm babies. Vision loss prevention requires timely screening and follow-up. Parental awareness is crucial to eye care compliance. In Northern India, insufficient parental knowledge and socio-economic challenges delay follow-up, increasing the likelihood of vision-threatening disorders.

**Method:** This 1-year retrospective, hospital-based study was undertaken at the Regional Institute of Ophthalmology (RIO), IGIMS, Patna (April 2024–March 2025). 200 ROP-diagnosed infant parents were questioned using a systematic and validated questionnaire. Demographics, ROP awareness, screening and follow-up knowledge, information sources, and follow-up challenges were collected. For clarity, questions were held in Hindi/Magahi. Descriptive statistics summarised data, and Chi-square tests and other inferential analysis examined awareness levels and socio-demographic characteristics.

**Results:** Of the 200 participants, only 39% were aware of ROP before initial screening. Most common sources of awareness included neonatologists (45%) and healthcare staff. Follow-up compliance was observed in 71% of infants, with dropouts largely due to financial burden (26%), lack of understanding (22%), and transportation issues (19%). A significant correlation was found between parental education and ROP awareness ($p < 0.01$). Income level also influenced compliance. Barriers to follow-up were more prominent among parents with low literacy and from rural areas.

**Conclusion:** The study emphasizes the need for targeted parental education programs within NICUs and the incorporation of structured follow-up reminder systems to improve ROP screening compliance. Community health workers must be trained to reinforce awareness at the grassroots level. Interventions addressing socio-economic and logistical challenges are vital to reduce preventable blindness due to ROP. Multi-centric and longitudinal studies are recommended to validate and scale effective strategies.

***Keywords:*** *Awareness, Compliance, India, Infants, Parental Knowledge, Prematurity, Tertiary Care*

## 1. INTRODUCTION

Retinopathy of Prematurity (ROP) is a potentially blinding eye disorder that primarily affects premature infants with low birth weight and early gestational age [1]. It is characterized by abnormal development of retinal blood vessels, which may progress to retinal detachment and permanent visual impairment if left untreated. Globally, ROP is one of the leading causes of preventable childhood blindness. With the advancement of neonatal intensive care and improved survival rates of preterm infants, the incidence of ROP has risen, particularly in low- and middle-income countries such as India [2].

The key risk factors for ROP include prematurity (birth before 34 weeks of gestation), low birth weight (less than 2000 grams), prolonged oxygen therapy, sepsis, and blood transfusions. The condition is often asymptomatic in its early stages, making timely screening and prompt intervention crucial. The window for effective treatment is narrow; hence, early diagnosis through regular ophthalmic screening and strict follow-up schedules are critical in preventing disease progression and preserving vision.

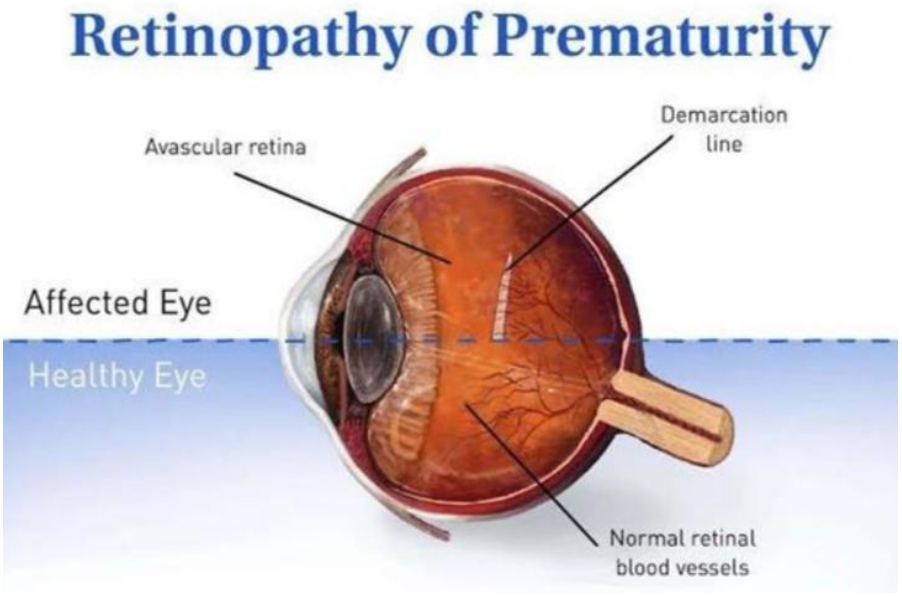


**Figure 1 Retinopathy of Prematurity (Source: [3])**

Parental awareness and understanding of ROP significantly influence adherence to screening protocols and follow-up appointments. Lack of awareness about the disease, its consequences, and the importance of timely screening often leads to missed appointments and treatment delays [4]. Cultural beliefs, socioeconomic challenges, and communication gaps between healthcare providers and families further contribute to poor compliance, especially in rural and underserved populations.

India faces a major public health issue with ROP. Although national ROP screening criteria exist, regional implementation varies. In Northern India, especially Bihar, newborn morbidity is significant and carer ROP awareness is low. Limited access to specialised eye care centres, untrained staff, and poor parental knowledge compound the problem. As a tertiary eye care centre, Regional Institute of Ophthalmology (RIO) at Indira Gandhi Institute of Medical Sciences (IGIMS), Patna helps fill this gap.

This study aims to evaluate parental awareness about ROP and assess compliance with follow-up care among parents of affected infants at RIO, IGIMS. Understanding these aspects will help identify barriers to compliance and inform targeted strategies to improve early detection and treatment outcomes for ROP in this region.

**Objectives**

- To assess parental awareness about ROP screening.
- To evaluate follow-up compliance and associated factors.

**Overview of Retinopathy of Prematurity (ROP)**

ROP, a potentially blinding eye condition, mostly affects premature, low-birth-weight, and intensively cared-for infants. Abnormal vascular growth in the young retina can cause retinal detachment and permanent vision loss if detected or untreated [5]. ROP has been rising worldwide, especially in middle-income countries like India, due to improving preterm neonatal survival but inadequate neonatal ophthalmologic infrastructure and awareness [6].

**Importance of Timely Screening and Follow-Up**

Timely screening and management of ROP are critical in preventing irreversible vision loss. The American Academy of Pediatrics and Indian National Neonatology Forum recommend that all infants born ≤34 weeks gestation or weighing ≤2000g undergo retinal screening within the first 4 weeks of life [7]. A study by [8] emphasized the importance of initial screening followed by strict compliance to follow-up appointments to detect disease progression and initiate treatment such as laser therapy or anti-VEGF injections as needed.

**Parental Awareness and Its Role in ROP Management**

Parental awareness is a cornerstone in ROP management, as screening and follow-up are outpatient-based services. Studies across different settings consistently show that inadequate parental knowledge is a major factor contributing to missed appointments and delayed treatment. A prospective study by [9] in rural Karnataka revealed that only 27% of parents had heard of ROP, and only 15% could articulate its consequences. In a similar vein, [10] found that only one-third of caregivers in a tertiary eye hospital in Eastern India were aware of the importance of ROP screening, despite their infants being at high risk.

**Sources of Information and Influence of Healthcare Workers**

Healthcare providers, especially neonatologists and nurses, play a key role in imparting ROP-related information. A study conducted by [11] observed that parental awareness was significantly higher when NICU staff were proactive in counseling. In contrast, reliance on informal sources such as the internet or peer parents led to misinformation or confusion.

**Barriers to Follow-Up Compliance**

Socioeconomic, cultural, and logistic barriers greatly influence follow-up compliance. Common deterrents include distance to the hospital, transportation issues, low literacy, lack of understanding about the disease, and cost of travel or treatment. In a North Indian study by [12], nearly 40% of infants missed their follow-up appointments due to lack of perceived urgency among caregivers.

**Effectiveness of Educational and Interventional Strategies**

Several interventional studies have demonstrated that structured education improves outcomes. For example, [13] implemented a tele-ROP program in Karnataka using portable imaging devices and parental counseling, which resulted in higher screening and follow-up adherence. Uttar Pradesh piloted a mobile app–based reminder system, which showed improved follow-up rates among low-income families. These models highlight the potential of technology and community-based education in bridging the awareness and compliance gaps.

While much research has been done in southern and western India, limited data is available from the Northern belt, particularly Bihar. Moreover, most existing studies focus on hospital-based ROP prevalence or clinical outcomes, with fewer focusing on caregiver behavior and awareness. This creates a significant gap in understanding the social dimensions of ROP care, which are critical for designing public health policies and educational programs.

## 2. MATERIALS AND METHODS

**Study Design**

This research was conducted as a retrospective study utilizing medical records of infants diagnosed with ROP and their parental data at a tertiary eye care center. The study aimed to assess the level of parental awareness regarding ROP and evaluate compliance with scheduled follow-up visits after initial diagnosis and treatment recommendations.

**Place of Study**

The study was carried out at the Regional Institute of Ophthalmology (RIO), Indira Gandhi Institute of Medical Sciences (IGIMS), Patna, a tertiary referral center in Northern India that provides specialized care for neonatal and pediatric ophthalmic conditions, including ROP.

**Duration**

The study covered a period of one year, from April 2024 to March 2025, allowing for a comprehensive analysis of cases diagnosed and followed up during this time.

**Sample Size**

A total of 200 parents of premature infants diagnosed with ROP at RIO, IGIMS were included in the study. The sample was selected based on availability of complete medical records and willingness to participate in the survey component of the study.

**Inclusion Criteria**

- Parents of premature infants diagnosed with ROP who had attended at least one eye screening session at RIO.
- Availability of complete contact and follow-up records.

**Exclusion Criteria**

- Parents who were unwilling to provide informed consent for participation.
- Parents with language barriers or cognitive limitations that hindered meaningful communication and data collection.

**Data Collection Tools**

Data were collected using a structured, pre-validated questionnaire designed to capture key domains related to parental knowledge and behavior. The questionnaire included sections on:

- Demographic profile of the parents
- Awareness and understanding of ROP
- Primary sources of information about ROP and eye screening
- Knowledge of ROP screening schedules
- Compliance with recommended follow-up visits
- Reported barriers to attending follow-up appointments (e.g., financial, logistical, or informational constraints)

**Ethical Considerations**

The study protocol was reviewed and approved by the Institutional Ethics Committee of IGIMS, Patna. Prior to participation, informed written consent was obtained from all respondents. Confidentiality and anonymity of patient and parental data were strictly maintained throughout the study.

**Statistical Analysis**

Data collected from the questionnaires were entered into Microsoft Excel and analyzed using SPSS (Statistical Package for the Social Sciences). Descriptive statistics such as means, frequencies, and percentages were used to summarize demographic variables and awareness levels. For inferential analysis, the Chi-square test was applied to examine associations between parental awareness and categorical variables such as education level, socioeconomic status, and follow-up compliance. Where applicable, logistic regression was employed to identify significant predictors of follow-up adherence. A p-value of $<0.05$ was considered statistically significant.

## 3. RESULTS

**Demographic Characteristics**

Out of the 200 parents surveyed, the majority were mothers (68%), with fathers comprising 32%. The mean age of respondents was 28.4 ± 4.7 years. Regarding education, 30% had completed only primary education, 44% had secondary-level education, and 26% had attained higher education (graduate and above). Socioeconomic status, assessed using a modified Kuppuswamy scale, revealed that 48% belonged to the lower socioeconomic class, 36% to the middle class, and only 16% to the upper class. Most families (72%) resided in rural or semi-urban areas within Bihar and neighboring districts.

**Table 1 Demographic Characteristics of the Parents (n = 200)**

| Variable | Category | n | % |
|---|---|---|---|
| **Gender** | Male | 64 | 32% |
| | Female | 136 | 68% |
| **Mean Age of Parent** | 28.4 ± 4.7 years | | |
| **Educational Status** | Primary (≤ Class 5) | 60 | 30% |
| | Secondary (Class 6–12) | 88 | 44% |
| | Graduate and above | 52 | 26% |
| **Socioeconomic Status** | Lower | 96 | 48% |
| | Middle | 72 | 36% |
| | Upper | 32 | 16% |
| **Residence** | Urban | 56 | 28% |
| | Rural/Semi-Urban | 144 | 72% |

**Awareness Levels**

Among the 200 parents, only 78 (39%) were aware of Retinopathy of Prematurity (ROP) before their infant's screening. Awareness levels varied significantly by educational background and socioeconomic status. Among parents with higher education, 69% had prior knowledge of ROP, compared to only 21% among those with primary-level education. The primary sources of awareness included neonatologists (52.6%), nurses (18%), ASHA workers (12.8%), the internet or social media (9%), and other parents or family members (7.6%).

**Table 2 Awareness of ROP and Source of Information (n = 200)**

| Variable | Category | n | % |
|---|---|---|---|
| **Aware of ROP (before screening)** | Yes | 78 | 39% |
| | No | 122 | 61% |
| **Source of Awareness** | Neonatologist | 41 | 52.6% |
| | Nurse | 14 | 18% |
| | ASHA Worker | 10 | 12.8% |
| | Internet/Social Media | 7 | 9% |
| | Family/Friends | 6 | 7.6% |

**Screening and Follow-up Compliance**

Of the 200 infants diagnosed with ROP, 71% (n = 142) completed the full course of recommended screening and follow-up visits. However, 29% (n = 58) dropped out before completing the recommended care. The main reasons for non-compliance included travel difficulties (41%), financial constraints (29%), lack of understanding about the importance of follow-up (17%), and family/social barriers (13%).

**Table 3 Screening and Follow-Up Compliance (n = 200 infants)**

| Follow-up Status | | n | % |
|---|---|---|---|
| Completed all follow-ups | | 142 | 71% |
| Dropped out | | 58 | 29% |
| **Reasons for Dropout** | **n** | **% (of dropouts)** | |
| Travel difficulties | 24 | 41.3% | |
| Financial constraints | 17 | 29.3% | |
| Lack of awareness | 10 | 17.2% | |
| Family/social barriers | 7 | 12% | |

**Association Analysis**

Chi-square analysis demonstrated a statistically significant association between parental education and ROP awareness ($p < 0.001$), as well as between socioeconomic status and follow-up compliance ($p = 0.004$). Parents in the upper and middle socioeconomic groups were more likely to adhere to follow-up protocols. Logistic regression further identified parental education as a significant predictor of both awareness (OR = 2.6, 95% CI: 1.5–4.5) and follow-up compliance (OR = 1.9, 95% CI: 1.2–3.2). Barriers to compliance were most prominent among rural, less-educated parents, highlighting the critical role of structured counseling and outreach services.

**Table 4 Association Analysis – Parental Education and Awareness**

| Parental Education | Total (n) | Aware (n) | Awareness % | p-value |
|---|---|---|---|---|
| Primary (≤ Class 5) | 60 | 13 | 21.7% | |
| Secondary (Class 6–12) | 88 | 31 | 35.2% | < 0.001 |
| Graduate and above | 52 | 36 | 69.2% | |

**Table 5 Association Analysis – Socioeconomic Status and Follow-Up Compliance**

| Socioeconomic Status | Total (n) | Compliant (n) | Compliance % | p-value |
|---|---|---|---|---|
| Lower | 96 | 56 | 58.3% | 0.004 |
| Middle | 72 | 58 | 80.6% | |
| Upper | 32 | 28 | 87.5% | |

## 4. DISCUSSION

This study observed on the significant gaps in awareness, screening compliance, and parental understanding of ROP among families attending a tertiary care institute in Northern India. Among the 200 parents surveyed, only 39% had prior awareness of ROP, and although 71% adhered to follow-up recommendations, a concerning 29% dropped out before completing treatment protocols. The findings underscore the need for structured educational interventions and support mechanisms to mitigate the risks associated with ROP-related blindness in preterm infants.

### Comparison with Indian and Global Literature

Our findings align with several Indian studies highlighting poor awareness levels among caregivers of high-risk neonates. For instance, a 2021 study conducted at AIIMS, New Delhi, reported ROP awareness among parents to be approximately 41%, closely mirroring our results [14]. A study in Tamil Nadu found that only 33% of caregivers had prior knowledge of ROP [15]. These numbers are significantly lower than awareness rates reported in developed nations. In a study from Canada, for example, parental awareness was reported to be above 75%, primarily due to effective communication strategies by neonatal intensive care units (NICUs) and integration of ROP education into postnatal counseling.

Screening and follow-up compliance in our study (71%) is moderately higher than some earlier Indian studies, which reported follow-up rates as low as 50–60%. This may be attributable to the institutional setting of IGIMS, Patna, where ROP screening is prioritized and reinforced through neonatology referrals. Globally, structured screening programs backed by government protocols have led to over 90% compliance rates in countries like Sweden and the UK, further emphasizing the disparity and the need for systemic change in low-resource settings [16].

### Gaps in Awareness and Reasons for Non-Compliance

One of the major gaps revealed through this study is the lack of structured parental education during the NICU stay. While neonatologists were cited as the main source of ROP information (52.6%), other health workers such as nurses and ASHA workers played only a limited role. This indicates a missed opportunity in leveraging the full healthcare workforce to disseminate vital information.

Reasons for non-compliance were multifactorial: travel difficulty (41%), financial burden (29%), poor understanding of the condition's seriousness (17%), and family/social barriers (13%). These findings highlight both logistical and informational gaps. In particular, rural parents struggled with long distances to tertiary care centers, while many caregivers lacked the literacy to comprehend medical advice fully.

### Limitations of the Study

This study has limitations. As a single-center, hospital-based study, the results may not apply to the general population. The IGIMS, Patna population may have different healthcare access or awareness than other places. Recall bias is also a risk, especially when parents are queried about prior information or missed follow-ups. Parents may have underreported awareness to avoid judgement or over-reported cooperation to impress the interviewer. The cross-sectional study also makes causality between awareness and compliance difficult to establish. Even though the questionnaire was verified and administered in local languages, subtle understanding may have been lost, especially among low-literate parents.

**Strengths of the Study**

Despite these limitations, this study has several notable strengths. It addresses a highly relevant public health issue in a region with limited prior data. The face-to-face interview method, using trained staff and local languages, allowed for deeper engagement and more accurate data capture. By including a sizable sample of 200 parents, the study offers robust insights into the socio-demographic and systemic factors affecting ROP care in Northern India.

Multidisciplinary collaboration, community engagement, and policy-level attention are essential to address the avoidable burden of childhood blindness due to ROP. Future studies should explore the impact of structured awareness programs, use of technology for follow-up, and broader community health worker involvement to create a more effective and equitable ROP care ecosystem.

## 5. CONCLUSION AND RECOMMENDATIONS

This study highlights significant gaps in parental awareness and follow-up compliance regarding ROP among caregivers at a tertiary eye care centre in Northern India. Despite moderate follow-up rates (71%), a large proportion of parents (61%) were unaware of ROP prior to screening, with lack of education, financial constraints, and poor understanding identified as key barriers. These findings underline the urgent need for integrating structured parental counseling and early education into neonatal care protocols. Counseling sessions should be initiated at the NICU level, using simple language and visual aids, with reinforcement during discharge and subsequent visits. To improve follow-up compliance, implementing reminder systems such as SMS alerts or scheduled phone calls can be beneficial, especially in rural settings where dropout rates are higher. Additionally, training community health workers like ASHA and Anganwadi staff to deliver ROP-related information and track post-discharge follow-ups can create a sustainable support system. Given the study's single-centre limitation, future research should explore multi-centric, longitudinal, and interventional study designs across diverse geographical areas in India to evaluate the effectiveness of such strategies on improving ROP outcomes. These efforts are essential to reduce the preventable burden of childhood blindness and ensure that every preterm infant receives timely and adequate ROP care.

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